

On-line supplement: RESEARCH IN PROGRESS: PUT THE ORPHANAGE OUT OF BUSINESS

There has been widespread interest in paediatric interstitial lung disease over many years. Important initiatives have included European [E1] and UK [E2] wide surveys which were arguably the first European attempts to address these rare lung diseases. This was the stimulus for a European Respiratory Society taskforce, published in 2004 [E2]. Other important initiatives have been the British Paediatric Orphan Lung Disease Registry [E3], and the French [E4] and German registries [E5]. During this odyssey, there has been increasing emphasis on central evaluation of these rare conditions, drawing on wider expertise than could be expected in a single centre.

References

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E3. Clement A, Allen J, Corrin B, et al. Task Force on chronic interstitial lung disease in immunocompetent children. *Eur Respir J* 2004; 24: 686-697

E4. Lavery A, Jaffé A, Cunningham S. Establishment of a web-based registry for rare (orphan) paediatric lung diseases in the United Kingdom: the BPOLD registry. *Ped Pulm* 2008; 43: 451-456

E5. Nathan N, Taam RA, Epaud R, et al; French RespiRare® Group. A national internet-linked based database for paediatric interstitial lung diseases: the French network. *Orphanet J Rare Dis*. 2012; 7: 40.

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